VISIONS

# Vision:

The act or power of seeing Sight

The special sense by which the qualities of an object fas color, luminosity shape and sizel constituting its appearance are perceived and mediated by the eye

# Vision

The act or power of imagination Mode of seeing or conceiving Unusual discernment or foresight



There is only one international organization which has adopted as its mission the prevention and treatment of blinding retinal degenerative diseases and the hope of vision through vision

# MESSAGE FROM THE BOARD

hile research into the workings of the eye have been ongoing for thousands of years, it is only within the last ten years that a formalized concentrated approach to retinal degenerative diseases has been instituted. With the formation of the National RP Foundation in 1971 and the dedication of the Berman-Gund lab in 1974, research specifically geared for this one family of blinding eye disorders began

The field of medical research is much like the corporate business arena. To succeed in either involves a great deal of personal and professional risk and large investments of both time and money in the end, there are no guarantees that either effort will succeed.

In ten short years, the field of research into retinal degenerative diseases has grown a hundredfold The RP Foundation has been the driving force behind this growth By providing direction and coordination through the leadership of its Scientific Advisory Board, an expanding series of research projects have been undertaken in an organized, focused approach—each subsequent project building on the success or failure of the previous one

These individual investigative efforts have all been undertaken within the context of an extraordinary spirit of cooperation Case information medical histories and results are all shared and discussed and evaluated—in almost constant dialogue

The Foundation is philosophy to provide "seed money finitial investment capitall for promising research efforts has proven successful in triggering federal support through the National Eye Institute Each dollar raised by

the Foundation has actually produced additional dollars for retinal research

Now with this report as we look back on the first ten years we see major accomplishments

- a growth in the number of talented eye specialists who have dedicated their work their ideas and techniques to these problems
- a revolution in the testing of individuals to diagnose retinal degenerative diseases
- a greater awareness of the number of people who are affected the needs of these individuals and their ability to persevere

Net with these developments we are impatient with the rate of our progress—and we will remain impatient as long as hundreds of thousands of people continue to lose their vision to these insidious ever disease.

As we enter our second decade, our goal continues to be "the discovery of the cause prevention and treatment of retinitis pigmentosa and other inherited retinal degenerations." In order to achieve this goal, the Foundation must broaden substantially its sources of financial support. This is our commitment for the eighties.

Jerome S Cardin Gharman Bur La Gordon Gund Vice Chairman

Bernard Bernard Bernard

Bernard Berman



Electron microscopes provide the ultimate in sophisti cated analysis of retinal structure

#### Officers and Trustees Jerome S. Cardin, Chairman, T. G. H.

Alexander Yankelowe Court of 2.5 Edmund P Bentz 1 Louise Briardman 2.9 Irving W Cushner 5 8 Steward Flaschen Ph D 7 1

George Russel Ir 5 Stephen A Wynn 6 7



Ocular examinations with special Instruments provide specialized clinical Information on patlents with Retinitis Plementosa and related retinal degenerations

report, the RP Foundation begins its 11th year of operation While most organizations arrive at such thresholds with triumph, ours, as might be expected is a bittersweet distinction. We are proudof the distance we have come but disappointed that our quest for such difficult answers is still incomplete Our initial zeal and enthusiasm for success has been replaced with a determined realization that continuing a methodical approach will work and our goals will be achieved!

Our initial vision has been clarified with additional research knowledge and refocused by our commitment to succeed

We have reaffirmed the fact that the multi-disciplined research approach wherein researchers in various fields share their knowledge does produce results Increasingly our researchers con-

tinue to be recognized for their creative, industrious efforts in their respective fields

During this past year the Foundation's achievements include the following

- · A new Director of Development was hired to develop and expand a national fundraising effort for corporations and
- · A Human Services Program which established new goals and dimensions and increased the national registry substantially
- An extensive coordinated Public Awareness Program which reached an audience in excess of 140 million people during the past year

No Executive Director's report would be complete without the appropriate word of thanks to

the 22,000 volunteers working around the country the national who assist them and the National Board of Trustees

Dennis L. Hartenstine

Executive on the



Through careful study and experimentation with ocular cells and tissues, research centers all over the world continue to detect clues to the mechanisms of retinal degeneration ignificant progress towards understanding the causes of retinal degenerative diseases has been made by the RP Foundation research program to date This section of the report prepared by Dr. Alan Laties M.D. Chairman of the Scientific Advisory Board, describes much of the important work contributed to this significant progress

## I GYRATE ATROPHY TREATMENT TRIAL

Gyrate Atrophy is a somewhat rare form of retinitis pigmentosa Recently. RP researchers have discovered that the cause of this condition is linked to a defective enzyme. As a result, a trial treatment program based on diet regulation has been developed.

2 RETINITIS PIGMENTOSA PIGMENT EPITHELIUM RESEARCH

The retina is lined by a spe-

cialized cell layer called the retinal pigment epithelium (RPE). Through recent studies using animals it is now known that the actual fault in retinal degeneration occurs in this specialized layer of cells rather than in the rods and cones of the retina itself. A delicate difficult process has been undertaken successfully in three RP Centers to study the RPE's biochemistry.

## 3 EARLY DIAGNOSIS

Pioneering work in examination, classification, and diagnosis of retinitis pigmentosa and allied hereditary retinal degenerations has been done in several of the RP centers. These efforts are crucial to progress toward the understanding of the causes of hereditary retinal degenerations.

#### 4 TAURINE

An essential amino acid for vision. Although its specific func-

tion is not known taurine is present in a normal retina in high concentration. When diet is deficient in taurine, cats progressively lose their vision. Simultaneously electroretinographic changes occur which are similar in several essential respects to those that occur in retinitis pigmentosa. The search continues for a link between taurine and some forms of hereditary retinal degeneration.

#### 5 VISUAL ACUITY

Most of us equate visual acuity with the ability to read Snellen letters—the familiar E charts used by eve doctors the world over Retinitis Pigmentosa Foundation supported eye research has recently shown that performance on the "E chart can be deceptive Providing an accurate measurement of an individual's ability to see low contrasts is important in the

evaluation of that person's disability and in planning a reasonable program to overcome it

## 6 BIOCHEMICAL ANALYSIS

make the most efficient use of donor eyes scientists at one RP center perfected a button technique. By this means a single donor eye servils as a source for thirty samples etch. If which in turn can be subject to biose chemical analysis. Needless to say this technique in agnifies the value of a donor exercity permittin as it does a marked increase in the efficiency. If use

		1980-81 Grants	1981-82 ommitments			1980-81 Grants	1981-82 Commitments
The Berman-Gond Laboratory for the Study of Retinal Degen- erations at the Massachusetts Eve and Far Infirmary Harvard Medical School Boston, MA	Fliot L. Berson, M.D. Princip II Investigator, Ross B. Edward Ph.D. Bernard Rosner, Ph.D. Susan Y. Schmidt, Ph.D. Michae, A. Sandberg, Ph.D. R. Bruce Szamier, Ph.D.	\$110373	\$131 (46)	offege of Physions & Sur- goons, Columbia University New York City, NY	leter Coura: M.D. Erncipal Investigator Mary Flood Ph.D. James Hale.	65 451	\$ 87,000
				University of III nois Eye & Lar Infirmary Chicago II	Gerald Fishman M.D. Principal Investigator Tose Cunha-Vaz. M.D. Roger I. Klingaman, Pl. D.	5 32 637	5 40 000
The New York University	Rehald Carr M.D. Principal Investigator Harris Ripps Ph.D. Irwin Siegel Ph.D. Manoucher Shakib M.D.	> 84 100	~ 43.823		R keleller S I Young Ph D		
Medical Center New York NY				Medical College of Virginia Virginia Commonwealth Univ Richmond, VA	Walter F. Nance, M.D., Ph.D. Principal Investigator inn. Boughman, Ph. P. Principal	\$ 51 923	\$ 45 996
The Wilmer Institute of The Johns Hopkins Hospital Baltimore MD	Daniel Finke stein M.D. Principal Investigator Fred Fitzle B Sc. James McCooplid Ph.D. Robert Massof Ph.D. Treine Maumenee M.D. Magda Reissie Ph.D. O. Simmel M.D.	< 79 252	5 75 547		Investigator		
The Jules Stein Institute of	Debora Larber Ph D. Principal	5 19 894	5 94 578	Other Activities:			
the University of California at Los Angeles This Angeles CA	Investigator Dean Bok Ph D David Chase Ph D Michael O Hall Ph D John Heckenli elv M Ph D Richard Lolley Ph D Roberth Meyers-Fillott Ph D			An mal La - lit .	For the acquisition care at 1 dis- tribution of dops with hered tan- retinial degenerations. The dogs are 1-pt at Federated Medical Resources, Honeybrook, PA	\$ 25,000	5 30 000
Institute of Ophthalmology University FLondon Moorlields Eye Hospital London England	John Marshall Ph.D. Principal Investigator Alan B.d. M.D. F.R.C.S. Principal Investigator Gallian Clover W.F. Frist David Facilizer (Barry law M. L. Ken p. D. Cowel, Man V. Saden	\$102 5 <b>95</b>	5100,000	Scientific Workshop	Clinicians were invited to participate at a workshop held in Saras stale Flaute discussional conformity in clinical testing and diagnotis	\$ 17,000	S 12 000
Cullen Eye Institute Ballin College of Medicine Hermann Eve Center University of Tevar Medical School Houst College Co	n nyestivator Charles A Garcia var. M.D. Pincip Unvestigator	1127 906	7137 56				
				Career Development Award.			
				िता की राज्य के विश्वास	Short of fram the con- other hound photosys in the fall of market Pl	\$ 32 624	5 43 209



#### Scientific Advisory Board

Agricat Mill hamin March and Mil

Secretar

Marthia, Silven (R.
Bernad (R. Ini), M.
Edward (C. Ini),

Specialists in electrophysiology, anatomy blochemistry and genetics work together in a multidisciplined effort to explain the complex mechanisms involved in retinal function and deterioration



The RP Foundation has established Diagnostic laboratories specializing in electrophysiology, psychophysics, and photography in an effort to precisely monitor the functions of the retina and further explore special visual fields

he needs of individuals who suddenly discover that they are gradually losing their vision from degenerative diseases. of the retina grow with every different daily encounter The Foundation's Human Services program was developed to help these people to better deal with the difficulties which are unique to this group of progressive hereditable visual disorders Through this Human Services program individual questions are answered directly, service referrals are researched and developed and a large professional educational program is maintained The Foundation's confidential national registry is periodically surveyed for needs assessment and undated for research treatment information Supporting the needs of the visually handicapped population in legislative forums is a major component of the Foundation's

Human Services program Through such efforts, the Foundation has helped obtain third party payment of the ITT Night Vision Aid in a number of states

Through a major outreach program, screening centers for the Night Vision Aid have expanded from 13 to 17 in the last year This increases the opportunity for individuals to obtain screening of low vision devices such as the ITT Night Vision Aid

A cooperative program with the Corning Glass Works Corporation has resulted in the availability of new sunglasses for the patient with refundis programs a

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Also through the Human Services department plans were developed for a national conference which would draw to gether for the first time profess in a sign and researchers in the field and individuals from around the world.

A brochure geared to the newly diagnosed RP patient was developed and distributed to all eye doctors in the country. As a result hundreds of new patients were introduced to the Foundation during the latter part of the fiscal year.

The dialogue maintained through the Human Senices program is essential to both the growth of the Foundation and the expansion of its research program.

# VOLUNTEER NETWORK

Laving vision in research programs and in design of an organizational structure to combat an elusive problem like retinitis pigmentosa is of little consequence without the manpower to implement them Fortunately, the RP Foundation has. through its 60 affiliate groups. mobilized a workforce of over 22,000 dedicated volunteers The volunteers provide the energy cooperation and strength for the special event fundraisers, the health fairs, the bike-a-thons and countless other RP events At the same time, they provide morale and emotional support by acting as information and referral units for newly diagnosed people with retinitis pigmentosa. Usher s syndrome or macular degeneration

Importantly these volunteer hours liberate the RP Foundation from the necessity of a staff operation thus freeing up more dollars for critical research projects. A cooperative relationship between the national office staff field representatives and the local volunteer chapters is essential to the success of the Foundation's mission.

Over 22,000 volunteers throughout 42 local Chapters raise funds through special benefit programs, membership drives and federated campaigns.









Ron Glass



Burt Reynolds



Loni Anderson



Polly Holliday



Katherine Helmond

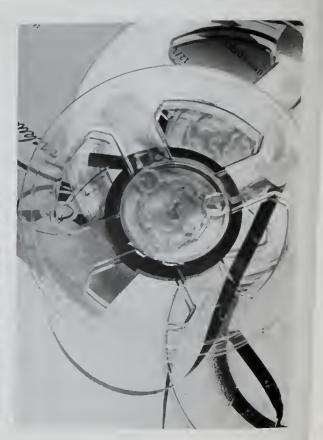


Barbara Eden



Gregory Harrison





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hat good is vision in research if it's kept secret? The Foundation's commitment to sharing information about RP research within the scientific community as well as to the general public is unique

Complementary to the professional education program is the Foundation's national public awareness program During the last year Polly Holliday (TVs "Flo") accepted the role of National Honorary Chairman and in this capacity appeared on a number of talk shows, including The John Davidson Show (Los Angeles) "Panorama" (Washington DC) and "People Are Talking" (Baltimore) She was also featured in a number of newspaper and magazine articles. For the first time. one of the Foundation's public service ads (featuring Polly Newsweek magazines and received national circulation totaling 7 million people

The Foundation through the cooperation of the cable USA Network received TV coverage during the NHF. Ice Hecker, Stanley Cup playoffs. All Star Bobby Smith and General Manager Le u Nanne of the Minnesota North Stars cooperated in the production of specially prepared spots.

The National Football League accepted the RP Foundation in its public service television and radio broadcasts for the Fall (81-82) season Phil Simms of the New York Giants is featured in the spot

Participating in the year's radio campaigns on over 4 000 radio stations nationwide were such celebrities as Burt Reynolds Carroll O'Connor David Brenner. Robert Merrill Nancy Marchand Polly Holliday Howard Hesseman lamie Farr Dr Jovce Brothers Tom

Brozaw I 1 I Britine Barbara Barrie Conrad Bair 101 Notan Pete Shaw and Conne-Streens

# TREASURER'S MESSAGE

n fiscal 1981, total combined unrestricted revenues of national headquarters and its affiliated chapters amounted to \$1,227,198, a 9% increase over fiscal 1980 Once again, this growth was made possible by the dedication and commitment of our volunteer network and the contributions of many individuals. foundations and corporations. Unrestricted program services expense increased 14% over 1980 from \$1 037 969 to \$1 188.467 This increase is due in large part to our continued expansion of research and human services

We are very proud to report that of the total revenues in fiscal 1981. 86% was expended for our program services (including 58% for research) 12% was expended for management and general expenses and only 7% for fund raising expenses. The total of these percentages exceeds 100% due to the \$76,181 deficit resulting principally from the increase in research grants.

awarded in fiscal 1981.

Total public support and revenues for fiscal year 1980 includes a \$630,000 restricted gift awarded to the Foundation to establish a professorship in ophthalmology for the study of retinal degenerations at Harvard University. In addition research expenses for fiscal year 1980 include a \$700,000 grant awarded by the Foundation to establish this professorship.

The Board of Trustees has approved planned expenditures for support of awards and grants to research facilities and other specific research programs (in addition to the grant awarded to Harvard University in 1980) for the three years ending June 30 1984 approximating \$3,100,000 Accordingly the Board has designated the total unrestricted current fund balance of \$1,272,095 at June 30, 1981 for research purposes. It is expected that expenditures under these research programs will approximate \$1,000,000 for the

year ending June 30, 1982

Our combined financial statements have been prepared in conformity with generally accepted accounting principles for voluntary health and welfare organizations and have been audited by Peat Marwick, Mitchell & Co. independent certified public accountants

The Retinitis Pigmentosa Foundation meets the standards of the National Information Bureau and the eligibility criteria set forth by the Office of Per

sonnel Management for partspation in the Combined Federa Campaign. The Foundation's programs continue to be recommended to the media by the Advertising Council Inc.

The national headquarters budget is reviewed and approved by the Board of Trustees

Salue W Cushner

Sallie W Cushner

HOW YOUR DOLLAR WAS SPENT BY NATIONAL HEADQUARTERS AND CHAPTERS IN FISCAL YEAR 1980-81

PROGRAM SERVICES

PUBLIC HEALTH & EDUCATION 19 59
HUV IN SERVICES 9 29

UPPOR' IN USERVICES

MANACIANENT & GENERAL 12%

ND RAIS NO 74



# FINANCIAL STATEMENT

NATIONAL RETINIES PIGMENTOSA FOUNDATION INC. AND AFEI HATE OCHAPTERS Combined Statement of Support, Revenue and Expenses and Changes, in Fund Balance Year ended June 30, 1981 with comparative totals for 1980.

	1981				
	Current fund		Build n and equipment	Tital all fin t	
	Unrestricted	Re-tricted	fund_	1981	1980
Public support and revenue Public support		Z 199.971		- 762 283	01 327 230
Contributions received from individuals corporations and foundations. Special events net of direct costs of \$269,864 in 1981 (\$232,255 in 1980).	628 912 435 636	5 133 371 ————————————————————————————————————		435 636	393 (4)3
Total public support	1 064 548	133 371	_	1 197 919	1 720 833
Grant from governmental agency	_	14 875		14 875	17 980
Interest income	162 650	39.251		201 901	_ 191 162
Total public support and revenue		187 497		414 695	1 929 975
Expenses Program services					
Research	818.083	_		818.083	1 405 136
Public health education	261 223	11 979	2 938	276 139	303.040
Human services	109 161	21 052	588	130 802	98 202
Total program services	1 188 467	33 031	3 5 2 6	1 225 024	1 806 378
Supporting services	164 119	5 040	1.763	170 924	6+427
Management and general Fund raising	90.938	3 404	588	94 928	69663
Total supporting services	255 057	8 444	2 351	265 852	232 030
Total expenses	1 443 524	41 475	5 877		52 045 408
Excess (deficiency) of public support and revenue over expenses	(2) 6 3261	146 022	(5.877)		
Other changes in fund balances—office furniture and equipment acquisitions					
from unrestricted current funds	16 4381		6 438		
Fund balances at beginning of year	1 494 859	82 221	25.875		
Fund balances at end of year	\$1 272 095	5 228 243	526-436		

For a complete copy of the audited combined financial statements as of and for the year ended June 30, 1981 please write to the National office

#### Affillate Chapters

#### Alabama

Briningham Chapter, 3508 Nazha Crick Mr. Rick Dodd President Ms. Escue Front

#### Arizona

Ms. Barbara Feldman

Orange County Chapter 14839 Jale 3 Rd

#### California

San Francisco Boy Area Chapter, 1960 California St. San Francisco CA 94109 415-397 3400-Weik

# Connecticut

District of Columbia

#### Fiorida

North Miami Beach Et 33160 305 947 3875

Mrs. Rebecca Maze eich: President

#### Georgia

1322 Brianwood Rd. N.E. Apt. 18B. Atlanta.

Illinois

#### Indiana

## Kentucky

Louiss de Chapter 8804 Marksfie d.R. ed.

## Louislana.

sur oral horses PO Box 73686 Merson 3

#### Maryland

Mid-Shore Chapter, Rt. Box 97, Church H.L. M.

#### Massachusetts

#### Michigan

Michigan Chapter, 1990 East Lincoln, Birmingham

#### Missouri

## Nevada

## New Jersey

#### New York

Be x 4 or 1 1 234 212-434 145

Manhartan Chapter P. Box 229 Cracie Square Mr Armui Browbinder Fresident

#### North Carolina

Predmint Chapter 1, 20 East Wendown Ave.

#### Ohlo

ureater Cleveland Chapter 12401 Oaksiew Bood Mrs Pat Santin President

#### Pennsylvania

Aller Town-Bethlehem-East un 3550 Rock, Lane Greater Philade phia Chapter 2033 Ea · Anaona St. Philadelphia PA 19125 215-739-8042

#### Rhode Island

Rhode Mand Charrier PO Box I 14 Hope Valley

#### South Carolina

Blue Ridge Chapter 250 Lowndes Ave. Greens le

#### Tennessee

West Tennesses Chapter 583.1 At Menaph

#### Texas

Dall as Chapter 4626 Mill Creek Frad Mr. Danald Funt, President

#### Utah

#### Virginia

#### Washington

#### Wisconsin

#### Volunteer Information Resource Centers

#### Alabama

Mr Tom E hott Pril Box 388 M s This Al-

#### Alaska

#### California

Mr Bolt Martin 3172 V. for St. Autora C. 80001

Ms. attitude im 45 573 Awarene Way Karkins

#### Maine

Michigan

Ms Besen Break 1955 Ferris Street SA Trind

#### Montana

#### New York

#### Ohio

the fire the street of her

#### Oklahoma

#### Oregon

#### Pennsylvania

#### Texas

Str. Ph. Leen. F. Box (" #14 Fixt W. rth. TX.

#### Wyoming

#### Foreign RP Foundations

#### Argentina

## Canada

## India

#### Israel

#### South Africa

#### Switzerland

#### United Kingdom

#### West Germany





National Retinitis Pigmentosa Foundation, Inc 8331 Mindale Circle Baltimore Maryland 21207 301-655-1011 TDD-301-655-1190 (for deaf)



VISIONS

1981



The needs of individuals who suddenly discover that they are gradually losing their vision from degenerative diseases of the retina grow with every different daily encounter. The Foundation's Human Services program was developed to help these people to better deal with the difficulties which are unique to this group of progressive hereditable visual disorders.

Through a major outreach program, screening crimers for the Night Vision Aid have expanded from 13 to 17 in the last year. This increases the opportunity for individuals to obtain screening of low vision devices such as the FTT Night Vision Aid.

A cooperative program with the Corning Glass Works Corporation has resulted in the availability of new sunglasses for the patient with retinitis pigmentosa.

For the first time, a survey was undertaken to determine the unique needs of young people who have retinal degenerative diseases.

Also through the Human Services department, plans were developed for a national conference which would draw together, for the first time, professionals and researchers in the field and individuals from around the world.

A brochure geared to the newly diagnosed RP patient was developed and distributed to all eye doctors in the country. As a result, hundreds of new patients were introduced to the Foundation during the latter part of the fiscal year.

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# Volunteer Information Resource Centers (VIRC's):

Juneau, AK Noagara Falls, NY 907-586-2493 716-284-6200 Muscle Shoals, AL Trotwood, OH 205-381-1110 513-854-2020 Fresno, CA Tulsa, OK W-209-486-1490 918-663-5555 H-209-22\*-6036 Portland, OR Kanoche, III 503-222-7483 808-247-0970 Mechanicsburg, PA Syracuse KS 717-761-4907 316-384-7430 Pittsburgh, PA Millinocket, MI: 412-923-1692 207-723-4338 Fort Worth, T.N. Grand Rapids, MI 616-784-9281 Casper, WY Minneapolis, MN 307-234-2534 612-338-0880

Black Eagle MT 406-562-3542

## Grants

	Grants	1981-1982 Commitmen
Institute of Ophthalmology, University of Landon, Moorfields Eye Hospital, London, England	\$102 595	\$100,000
College at Physicians & Surgeions, Columbia University, New York City, NY	\$ 65,451	\$ 87,000
Cullen Lye Institute, Baylin Callege of Mediutie, Hermann Eye Center, University of Texas Medical School, Houston, T	\$127,906 'X	\$137 156
University of Illimots Lye & Ear Infirmacy, Chicago, H.	\$ 32,tc37	\$ 40,000
Medical College of Virginta, Virginia Commonwealth Umv., Richmond, VA	\$ 51,923	\$ 45,996
The Berman-Gund Laboratory for the Study of Retinal Degenerations at the Massachusetts Eye and Em Infirmacy, Harvard Medical School Boston, M	\$110,373	\$131,146
The New York University Midical Center, New York, NY	\$ 84,100	\$ 43,823
The Wilmer Institute of The Johns Hopkins Hospital, Baltinure, MD	\$ 79,252	\$ 75,547
The Jules Stein Institute of the University of California at Los Angeles, Los Angeles, C.A.	\$ 49 894	\$ 94,5°8
Other Activities:		
Annual Facility	\$ 25,000	\$ 30,000
Scientific Workship	\$ 17,000	5 17,000
Career Development Award:		
Samnel G. Jacobson	\$ 32.624	\$ 43,200

# Treasurer's Message

In Its al 1981, total combined unrestricted reservoe of naional headquarters and its affiliated chapter, amounted to \$1.25°, 198. a 9%, increase over Its al 1980. I rice intered program services increased 14% over 1980 from \$1.03°, 969 to \$1,188,467 due to expansion of received, and horman systems.

We are very proud to report that of the total exercises received in local 1981, 86% was expended for our program services for bulling SOC for research. 12% was expended for management and general expenses and only 4% for finial training expenses. The total of these percentages exceeds 100% due to the \$250, BM definit resulting principally from the mercase in research figurals was added in 1854–1984.

For al public support and revenues for five il year 1980 indudes a \$6,00,000 restricted gift awarded to the Loundation recessablish a professorship in opticlabilities gift the study of remail begennations at Harvard University. In addition research expense for fival sear Pressure adea \$ 60.000 grant awarded to the Foundation to easily it is profesor hip

The Bord of Trustee has approved planned expectione for uppear of award, and grass to resear life face, and other specific research program. In addition to the grant awarded to Harvard University in 1999, for the tree years ending June 30, 1984 approximating \$3, 10, 300, cordingly the Board has designated their calculations are received our million of the Board has designated their calculations are received our million of the Board has designated their calculations. For example, the board of the programs will approximate \$1,000,000 for the conreduction \$0, 1982.

Sallie W. Go hner Vice President and Treasurer

## NATIONAL RETINITIS PIGMENTOSA FOLNDATION, INC AND AFFILIATED CHAPTERS

Combined Statement of Support, Revenue and Expenses and Changes in Fund Balances Year ended June 30, 1981

Year ended June 30, 1981	1981		Building		
Public support and cevenue. Public support Contributions received from individuals	Currer Unrestricted	nt funds Restricted	equipment fund	Tota 1981	l all funds 1980
corporations and foundations Special events, net ill direct costs of \$269.864	\$ 62% 912	133,3"1		762.283	
in 1981 (\$232 255 in 1980)	= 435 636			435,636	393.66
Total public support	1,064 148	133.3"1		1 197,919	1 2 1 4 1 2
Grant from governmental agency Interest informe	(62,650	14 575 39,251		14.8°5 201.901	7 9±0 191 162
Fotal public support and revenue	1,22" 198	[8149"		1,414 695	1 929 9~*
Expenses: Program services Research	818,083			n 5,1 n3	1 405 136
Public fiealth eilin atmn Human services	261 223 109,161	11 979 21,052	2 938 388	2*6 F39 F30 ×112	303,044 9= 202
final program services	1 188 40	33,031	3,526	1,225,024	1.806.3"H
Supporting services Management and general Fund rusing	164 H9 90 93s	5,04n 3.404	1,763	170,924 94 92k	169 42" 69 603
Total supporting services	255.05*	8,444	2.351	265 ×52	239 030
Foral expenses	1 443 524	41,475	5 A**	1,490,8~6	204° 40H
Excess (deficiency) of public up resenue over expenses	(216.326	146,022	5 877)		
ther changes in fund balances quipment a quisinons from unite	(6,438)		6,43#		
und balances at beginning of year	1,494 559	82.221	25,875		
und balances at end of year	\$1,2~2,095	228,243	26,436		
or a ramplete copy of the audit p	31,2 2,477				

With this annual report, the RP Foundation begins its 11th year of operation. While most organizations arrive at such thresholds with triumph, ours, as might be expected, is a bittersweet distinction. We are proud of the distance we have come but disappointed that our quest for such difficult answers is still incomplete. Our initial zeal and enthusiasm for success has been replaced with a determined realization that continuing a methodical approach will work and our goals will be achieved!

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- A new Director of Development was hired to develop and expand a national fundraising effort for corporations and foundations.
- A Human Services Program which established new goals and dimensions and increased the national registry substantially.
- An extensive coordinated Public Awareness Program which reached an audience in excess of 140 million people during the past year.

No Executive Director's report would be complete without the appropriate word of thanks to the 22,000 volunteers working around the country, the national staff and field representatives who assist them and the National Board of Trustees.

Dennis L. Hartenstine

While research into the workings of the eye have been ongoing for thousands of years, it is only within the last ten years that a formalized concentrated approach to retinal degenerative diseases has been instituted. With the formation of the National RP Foundation in 1971 and the dedication of the Berman-Gund lab in 1974, research specifically geared for this one family of blinding eye disorders began.

In ten short years, the field of research into retinal degenerative diseases has grown a hundredfold. The RP Foundation has been the driving force behind this growth. By providing direction and coordination through the leadership of its Scientific Advisory Board, an expanding series of research projects have been undertaken in an organized, focused approach—each subsequent project building on the success or lailure of the previous one

These individual investigative efforts have all been undertaken within the context of an extraordinary spirit of cooperation. Case information, medical histories, and results are all shared and discussed and evaluated—in almost constant dialogue.

The Foundation's philosophy to provide "seed" money (initial investment capital) for promising research efforts has proven successful in triggering lederal support through the National Eve Institute. Each dollar raised by the Foundation has actually produced addition of dollars for retinal research.

Now with this report as we look back on the first tenive irs, we see major accomplishments

 a grow him he rumber of talented eye specialists which ive dedicated their

- work, their ideas and techniques to these problems.
- a revolution in the testing of individuals to diagnose retinal degenerative diseases
- a greater awareness of the number of people who are allocted, the needs of these individuals and their ability to persevere.

Yet with these developments we are impatient with the rate of our progres—and we will remain impatient as long as hundreds of thousands of people continue to lose their vision to these insidious eye diseases.

As we enter our second decade, our goal continues to be "the discovery of the cause, prevention and treatment of retinitis pigmentosa and other inherited degenerations..." In order to achieve this goal, the Foundation must broaden substantially its sources of financial support. This is our commitment for the eighties.

Jagor ? Carllen

Jerry Cardin Churman

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Gordon Gund Vice Chairman

Benne Burn

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# VISIONS 1981

ANNUAL REPORT OF THE NATIONAL RETINITIS PIGMENTOSA FOUNDATION FOR THE YEAR ENDING JUNE, 1981

Vision: The act or power of imagination; mode of seeing or conceiving, unusual discernment for loresight.



There is only one international or organization which has adopted as or mission the prevention and treatment of blinding retinal degenerative diseases and the hope of vision through vision.

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